There was no reason I deserved a visit from an angel. I didn’t believe in them at the time, nor do I now. Nevertheless, as I walked from my doctor’s office in a haze of questions, fears, and old-fashioned misery, it was waiting for me. Waiting because a simple sentence had just laid waste to my plans, my dreams, my 43-year old life, “I think you have Parkinson Disease.”

How could I have Parkinson’s? How long could I simulate “normal”? When would I have to give up my job? What would this mean for my family? When should I tell my friends? The questions were silenced by a voice that rang with clarity and conviction. “You have to exercise!” the angel’s voice intoned, “or you will descend in no time in an ever-steeper spiral to complete incapacity.” The angel left me, in effect, with a little stone tablet bearing the 11th Commandment: “Move it or lose it.” It was a moment I think of as “The Visitation of the Spandex Angel.”

The Helplessness Antidote

Peter Dunlap-Shohl

Peter Dunlap-Shohl has worked as cartoonist for the Anchorage Daily News for over 25 years. He was diagnosed with Parkinson disease in 2002 and maintains a blog about living with Parkinson’s that features original cartoons and illustrations.

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How could I have Parkinson’s? How long could I simulate “normal”? When would I have to give up my job? What would this mean for my family? When should I tell my friends? The questions were silenced by a voice that rang with clarity and conviction. “You have to exercise!” the angel’s voice intoned, “or you will descend in no time in an ever-steeper spiral to complete incapacity.” The angel left me, in effect, with a little stone tablet bearing the 11th Commandment: “Move it or lose it.” It was a moment I think of as “The Visitation of the Spandex Angel.”

Where the angel got its information, I don’t know. This was over a decade ago, and though I burned up the Web in a search for something, anything, that could give me a straw to grasp, there was little there. Dr. Jay Alberts had yet to publish his signal discovery concerning tandem bicycling and the substantial symptomatic relief it can bring. There was no mention of the role Yoga, Tai-Chi and dance can play in aiding the crucial ability to balance, keeping us, PD patients, out of hospitals with broken bones. There was nothing about the value of boxing, or weight-training, or the big-movement strategy that now constantly make news in the Parkinson’s community.

I had nothing to go on beyond the urgent proclamation of my mystic visitor and the conviction that, with my body under assault by this mysterious and destructive disease, I had to do all I could to protect the underlying strength and ability to move that I still possessed. So it was a matter of faith for me to get out of bed each morning, climb on my elliptical trainer and go as fast and hard as I could for a half-hour, five times a week. But it wasn’t long before it was clear to me that I was seeing mitigation of my symptoms. My tremor visibly subsided after a good exercise session, and my speech improved. While out riding my bike, I would catch myself not only singing, but actually hitting the notes I was aiming for. And nothing dissipates the fog that rolls thick around my head in the mornings more effectively than exercise. These effects and the research that shows they are no mere fluke should be familiar gospel to anyone coping with PD.

But here are two additional reasons to move your body. The first, beyond the benefits cited above is, it just feels good.

continued on next page
The Helplessness Antidote continued from front page

Should the day come, at last, when Parkinson disease forces you into a wheelchair, you will at least have made the most of your ability to move while you could and probably made that window in time when movement was possible larger than it would have otherwise been. Second, until these recent discoveries about exercise, all we could do was manage our decline. We were told our disease was progressive, incurable, and disabling, and we were helpless to do anything to change it. Helpless. Exercise can liberate us from this deadly feeling, freeing our spirits as we free our bodies.

This article appeared in the NWPF publication on April 24, 2015, and is reprinted with permission of NWPF. Peter is a blogger in this wonderful weekly publication.

Managing Constipation in Parkinson Disease

Kathryne Holden, MS, RD, is a Registered Dietitian specializing in PD. She has authored many books about PD, including Eat Well, Stay Well With Parkinson’s Disease and Nutrition Matters.

Constipation is among the most common non-motor symptoms of Parkinson disease. It can occur years before diagnosis in some people. This happens when PD affects the autonomic nervous system that guides the movement of the muscles of our gastrointestinal tract, including the colon. The movement, called peristalsis, becomes slowed so that the stool moves more slowly through the colon.

The task of the colon is to receive watery indigestible residue from the small intestine and then, as the residue moves along, to remove some of the water. Gradually, as it travels through the colon, the residue becomes a soft, bulky stool that is easily passed. But when we don’t consume enough liquids or fiber, the residue is not as watery. The colon continues removing water, but the stool moves slowly. Too much water is removed, leaving a hard, dry stool that is difficult to pass. This is what we know as constipation.

Prolonged constipation can, in some people, affect medications. PD medications may fail to take effect. Then, when a bowel movement does occur, the medications can “kick in” within minutes. But until then, the person may experience prolonged “off time.”

How can constipation be prevented? When peristalsis is slowed, it becomes more important than ever to pay careful attention to daily meals. Highly-processed foods, made with refined flour and sugar, have been stripped not only of their natural minerals and vitamins, but of their fiber also. Avoid these highly processed foods. Instead, choose whole-grain breads, crackers, and breakfast cereals. Use honey, maple syrup or stevia for sweeteners rather than foods made with sugar and high-fructose corn syrup.

High-fiber foods Next, look for foods that are naturally high in fiber. Most vegetables and fruits contain a variety of fibers and pectins, all of which are important to our health. Raspberries, pears, and apples are among the highest-fiber fruits, while artichokes, green peas, broccoli, leafy greens, such as turnip greens and spinach, and sweet potatoes are high-fiber vegetables. Soluble fibers help control blood glucose; insoluble fibers keep the stool soft and bulky. Both may act as a substrate (“food”) for friendly bacteria in the colon.

Whole grains contain complex carbohydrates as well as fiber, and can be a valuable addition to the menu. Whole rye and whole wheat bread, oatmeal porridge, brown rice, and barley (preferably unhulled barley which is one of the highest-fiber grains) are excellent everyday foods.

Legumes (dried beans, peas, and lentils), seeds, and nuts are also extremely high in fiber as well as important sources of minerals, such as magnesium, and vitamins, such as folate. Legumes should be included in meals at least three or four times a week. Split pea soup, hummus, Cuban black beans, bean salads, casseroles, and refried beans are just a tiny fraction of the multiple ways to use and eat beans. If you have a pressure cooker, you can cook them yourself and control the salt and flavoring, but canned beans are inexpensive and perfectly good as well. Chia seeds, flaxseeds, sesame seeds, coconut, almonds, and sunflower seeds are all rich in both fiber and healthful fats.

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Mindfulness Works in Parkinson’s Patients

John Zapanta, PT, DPT, conducts research, and McKay Murdock, SPT, is a physical therapist intern at the Colorado Physical Therapy Specialists.

Past research has already shown that exercise can significantly reduce symptoms of PD and help a person move and feel better. However, the World Health Organization defines health as “a state of dynamic harmony between the body, mind and spirit of a person.” So is there more that we can do besides just exercise to counteract the effects of PD? Researchers respond with a resounding “yes!”

Enter mindfulness. Those who practice mindfulness have been shown to have enhanced immune systems, relief from chronic illnesses, decreased anxiety, better focus, increased satisfaction with exercise and even structural brain change, a process called neuroplasticity.

So what exactly is mindfulness? The exercise of mindfulness can include breathing, self-talk, visualization or more advanced methods such as tai chi and qi gong. By practicing mindfulness along with a physical fitness program, one may engage the whole body and mind to improve neuroplasticity.

Research on the benefits of mindfulness for neurologic diseases such as PD has exploded.

Long-term mindfulness practitioners increase the working capacity of the brain, connections within the brain and brain matter compared to non-practitioners. This suggests mindfulness may keep brains young and healthy. An eight-week mindfulness training program makes measurable changes in the brain structures associated with learning and memory, sense of self, empathy and stress. Only four days of mindfulness training can enhance the ability to sustain focused attention. It also shows significant improvements in mood, visuo-spatial processing, working memory, and cognition.

Dr. Norman Doidge, MD, a leading expert in neuroscience and medicine, has made some fascinating discoveries on the power of the mind, as described in his book, The Brain’s Way of Healing: Remarkable Discoveries and Recoveries from the Frontiers of Neuroplasticity. Dr. Doidge recounts the story of how his friend with Parkinson’s was able to normalize his walking pattern. He did this by slowing down his walking, using extreme “meditative” concentration to break apart each step, and practicing for a full year. He found that by bringing the movement into conscious attention, he was able to take advantage of different brain areas that were not affected by PD.

This same friend eliminated his tremors by being more aware of his movement. For example, he held his glass of water more firmly, fixed his handwriting by switching from cursive writing to printing capitals, and discovered that by holding his fork at 45 degrees toward himself that his tremor disappeared. Other brain stimulation activities he used included crosswords, Sudoku, bridge, chess, poker, dominoes, recording CDs of himself singing, and learning French.

A longtime practitioner of mindfulness for 10 years, Rob Piper, a Fort Collins, Colorado, resident, was diagnosed with PD in 2014. He describes mindfulness in his life to be “living in the present moment and not dwelling in the past or future.” Mindfulness has helped him acknowledge his thoughts and emotions by being more present and responding to them rather than reacting to them. Sometimes he feels anxious regarding the future of his PD, but he is able to use mindfulness training to calm his anxieties and have more control of his mind and body. He describes how breathing is a “natural tranquilizer” that makes him feel more focused during the day, improves his sleep at night, and makes him more consciously aware of his physical movements.

He describes being more conscious of all of his senses during exercise. He sees more clearly, feels the hiking poles in his hands and the rocks underneath his shoes, smells the fresh air, and hears nature around him. Rob considers mindfulness to be an integral and positive experience for both his physical and nonphysical symptoms of Parkinson’s and recommends it to those who are interested in practicing it.
Excessive Daytime Sleepiness in Parkinson Disease

Baijayanta Maiti, MD, PhD, Clinical Fellow, Movement Disorders Section, Department of Neurology, Washington University in St. Louis

Although the key motor symptoms of shaking, stiffness, paucity of movements and balance problems have traditionally received more attention and are quintessential features for the clinical diagnosis of Parkinson disease (PD), a mélange of non-motor symptoms including fatigue, anxiety, excessive daytime sleepiness (EDS), depression, pain, constipation, and bladder problems can often be more troublesome to the patient and at times can even precede the onset of motor symptoms.

EDS is one of the more common non-motor symptoms and greatly impacts the quality of life of PD patients, often by imposing another set of restrictions on their activities. The prevalence of EDS in PD patients has been reported to be anywhere between 15-75%. EDS has gained wide attention ever since the initial report in 1999 of sleep attacks in eight PD patients, all of whom suddenly fell asleep while driving. Incidentally, they were all taking dopamine agonists, a class of antiparkinsonian medication. Although a few studies have suggested a stronger association of EDS with these agonists than levodopa (another widely used antiparkinsonian medication), other groups have found it is the total amount of dopamine supplementation and not the specific category of drug that matters. Concurrent use of medications with sedative side effects could also worsen EDS, but EDS is not merely a treatment side effect. Few studies suggested that it could be a manifestation of PD itself and could worsen with disease progression; however, other studies have failed to prove this association. Several studies have also implicated multiple sleep problems to be contributing to EDS. These include:

- Restless leg syndrome (RLS, where there is an irresistible urge to move the legs due to an underlying unpleasant sensation, occurs usually during rest at night, and resolves with movement)
- Sleep fragmentation (multiple nocturnal awakenings either due to wearing off of levodopa resulting in stiffness or even emergence of shaking, or nocturia i.e., waking up multiple times in the middle of the night to go to the bathroom)
- Sleep apnea (multiple transient episodes of involuntary cessation of breathing during sleep)
- REM sleep behavior disorder (RBD, marked by dream enactment)
- Pain and sleep apnea syndrome also proved to be key contributory factors of EDS in this study.

If you develop excessive daytime somnolence, you should discuss it with your doctor. While there is insufficient evidence for pharmacologic treatment of EDS, stimulants like modafinil and caffeine have shown some benefit in small trials and could well be an option in carefully selected cases. However, there are other measures that could potentially improve EDS. Eliminating drugs with sedative side effects, whenever feasible, or optimizing the medication regimen often makes a significant difference. Pain can often be a sensory manifestation of PD itself or could be secondary to off-period dystonia, both of which could respond to levodopa dose adjustments. If there is a definitive temporal relationship of EDS with antiparkinsonian medication, minor dose adjustments or switching the drug class could be effective. Appropriately evaluating for and addressing comorbid sleep problems like sleep apnea, treating RBD with clonazepam, an extra dose of levodopa at bedtime to prevent nocturnal wearing off, or even simple measures like avoiding extra fluid intake after dinner to prevent nocturia could ultimately improve quality of sleep and potentially ameliorate EDS. Lastly, the merits of regular exercise cannot be overemphasized. It helps regularize the sleep wake cycle, prevent insomnia, manage body weight, and could thus have a significant positive effect on EDS in addition to its proven long-term global health benefits.
About 90% of people with Parkinson's will experience changes in their voices or their ability to make speech sounds during the course of the disease. These changes may make a person's speech less precise and more difficult to understand. Most commonly, the voice becomes quieter. Other symptoms include a narrowing of the vocal range resulting in monotone speech, difficulty sustaining breath while speaking, and/or a breathy or hoarse quality. The symptoms can lead to difficulty in communicating with family and friends as well as frustration on the part of the individual living with Parkinson's. In spite of all the changes occurring, one can affect a change and positively make a difference. There are a number of therapeutic interventions that research has shown can maintain and even improve one's voice.

One of the therapeutic interventions receiving increased attention is singing. In an exciting new research study conducted at Iowa State University, Dr. Elizabeth Stegemoller, Ph.D, MT-BC, examined the effects of structured singing on individuals with Parkinson’s. Prior to beginning her study, Dr. Stegemoller screened her participants to determine voice quality and swallowing ability. Additionally, each participant completed a quality of life survey. Over the course of eight weeks, individual groups met at four different study sights across Iowa. Several of the groups met twice weekly while others met only once a week. Each of the groups followed the same format for their rehearsals and was led by a music therapist.

The sessions began with a "hello song," after which the participants proceeded through a series of vocal exercises that focused on improving the muscles used in singing as well as swallowing. Once the warm-ups and exercises were completed, the groups sang a selection of familiar songs. A closing song completed each session. At the conclusion of the eight-week study, Dr. Stegemoller again assessed the participants for voice quality, swallowing, and quality of life. The results demonstrated a significant improvement in the areas of vocal volume, the ability to breathe in and out more efficiently, swallowing, and overall positive changes in quality of life. Her research gives strong support for the use of group singing when led by a certified music therapist.

According to Dr. Colum MacKinnon, PhD., Assistant Professor in Neurology at the University of Minnesota, “Data shows us that listening to music increases dopamine.” Michael S. Okun, M.D., University of Florida Health and Professor of Neurology, seems to agree with this statement, adding that “there is mounting evidence to support the idea that singing can benefit Parkinson disease patients, and Dr. Stegemoller’s study shows that benefits extend beyond just the voice, which is interesting and may have practical implications for the field.”

Any work towards strengthening the voice is vital to maintaining the ability to communicate and keeping the voice healthy. With the current research showing evidence of significant improvements in four distinct areas (voice volume, breathing, swallowing, and quality of life), why not consider joining a vocal group such as the Tremble Clefs? Tremble Clefs of Greater St. Louis meets each Saturday in Ladue from 1:30-3:00 p.m., and rehearsals follow much the same format as was outlined by Dr. Stegemoller.

Tremble Clefs of Greater St. Louis is in the process of conducting its own research. Under the guidance of Erin Foster, OTD, MSCI, OTR/L, Assistant Professor of Occupational Therapy, Neurology and Psychiatry at Washington University School of Medicine, Sarah Risso is currently conducting research with our Tremble Clefs group. Hoping to lend even more support to group singing, Sarah, MSOT/S, is directing the research as she completes work on her master’s degree in Occupational Therapy.

Dr. Stegemoller suggests the best way to incorporate music into your life is to listen to music, but not just any music – listen to your favorite preferred songs. “Sing in the car, sing in the shower. It doesn’t matter. Take time out of your day to sing whatever you want. It will help your mood and will work the muscles that affect swallowing and speech.” The Tremble Clefs group is always open to new members. If you or someone you know would like to consider joining the group, please call the APDA office 314-362-3299 for more information. Come, be part of the fun and sing your way to a better voice!
This year’s 17th Annual APDA Golf Classic in memory of Jack Buck, held on May 18, 2015, was our most successful fundraiser ever, raising just over $138,000 for patient services and Parkinson research. The event, with the generous assistance of Honorary Chair John Mozeliak and Auctioneer & Emcee Tom Ackerman, also served to increase the awareness of Parkinson’s in our local community. It was another great day for golfing at Algonquin Golf Club in Glendale!

Our success was attributed to our loyal sponsors: **CELEBRITY level sponsor:** Moneta Group; **MAJOR level sponsors:** Selequity, Sterling Bank, Teva Pharmaceuticals and Wells Fargo; **GOLF CART sponsors:** Carol House Furniture and KPMG; **CONTEST sponsors:** Benton Homebuilders Community Partnership, BJC HealthCare, Enterprise Bank & Trust, Express Scripts and Riverside Furniture; **LUNCH sponsors:** Scottrade and Dave & Suzie Spence; **COCKTAIL RECEPTION sponsors:** Budget Billboards, Inc./For Pete’s Sake, Delta Dental, Steve & Lynn Hurster, Merrill Lynch Wealth Management and the St. Louis Cardinals; **BEVERAGE/SNACK sponsors:** John & Jean Basilico, Centric Group, Gershman Commercial Real Estate, SE Farris Law firm; **DRIVING RANGE sponsor:** DTZ; and **HOLE sponsors:** Ameren, Argent Capital Management, Don Carlson, Cooperative Home Care, Larry and Sonya Davis, The Delmar Gardens Family, Express Scripts, Fastsigns of Bridgeton, Keith & Cindi Guller, Henges Interiors, Horner Shifrin, Husch Blackwell, Kodner Gallery, Missouri Cures Education Foundation, Petro-Mart/Western Oil, Inc., Reitz & Jens, Inc., Shillington Box Company, Serta Mattress Company. Our **EXCLUSIVE RADIO PARTNER** KMOX allowed us to market and promote the golf tournament, which also helped raise awareness of the APDA and Parkinson disease.

**CHARITABLE CONTRIBUTIONS** arrived in generous proportions from Jeff Fox, Larry and Gail Glenn, Suzanne Hurster Wood, Tom and Amy Mackowiak, George and Nancy Marble, Morgan Stanley, PJG and Associates, Marty Satz, Al and Alice Schott, Bob and Jennifer Schuller, Jack Strosnider, Marilyn and Bob Warren, George “Butch” Welsch, Bob and Lynda Wiens.

**AUCTION ITEMS** were donated by Tom Ackerman, Asymmetric Solutions, Autohaus BMW, Golf Discount of St. Louis, Gary Hoemann, Kyle Lucks, Mister Guy Clothiers, Dan McLaughlin, John Mozeliak and the St. Louis Cardinals.

Caps off to these special **VENDORS** who helped make the event a success: Autohaus BMW for the hole-in-one car; Crown Trophy for the crystal golf awards (in loving memory of Max April, Shale M. Rifkin, and Ben April); Fastsigns of Bridgeton (Barry Roufa) for the wonderful signage and pin flags; Zach Dalin and Bryan Schraier for their professional photography services; Pretzel Boy’s and the St. Louis Cardinals for hot pretzels and beverages on the course; and Tom Ackerman, Dan McLaughlin & John Mozeliak for media/marketing leading up to the sold-out event.
Doug Schroeder, a Boeing engineer diagnosed with early onset Parkinson’s, spoke to the crowd about optimism and PD. Dr. Perlmutter, the Medical Director of the Greater St. Louis APDA, Head of the Movement Disorders Section and a distinguished Movement Disorder Specialist at Washington University, shared with our golfers and dinner guests the hopefulness he feels as a scientist working to find causes and a cure for this disease. He also expressed his gratitude for the generosity and support provided as a result of this fundraising event. As a result of Doug’s inspiring story and Dr. Perlmutter’s speech, almost $26,000 was collected during the FUND-A-NEED portion of the evening from the charitable individuals/couples present: Todd Anstine, Matt Bayer, Kena Blanton, Dave Butler, Rich Chrismer, Jerry Clerc, Ed Dickinson, Laura Dobsch-Mayer, Anne Droese, Chris Edwards, Jim Gidcumb, Ed Goedeker, Patrick Hoene, John Hogan, Gil Hoskins, Kevin Kozminske, Matt LaMartina, Alex Lee, Alan Lemley, Mark McPeek, Jason Morris, Scott Mosby, Dean Mueller, Bob O’Connell, Brian Potter, Tim Potter, Bill Reller, Barry Roufa, Dave Sadler, Marty Satz, Rich Schindehette, Kurt Schoen, Kathy Schroeder, Matt Schumacher, Rich Schumacher, Ross Schumaker, Rich Smith, Sandy Steppig, Karen Vangya, Bob Warren, Bill Warren, Grant Washburn, Jim Whitledge, Jeff Wist and Marty Zygmund.

We can’t forget to thank our 136 golfers who had a great day on the greens, bidding on many wonderful auction items, enjoying the Question-and-Answer session with John Mozeliak and Tom Ackerman, and feasting on the dinner served by wait staff at Algonquin. Auctioneer Extraordinaire Tom Ackerman secured bids for our one-of-a-kind live auction items including a unique, signed painting of St. Louis Cardinals Hall of Famer Bob Gibson by Kyle D. Lucks; the opportunity to throw out the first pitch, dine in the Cardinal Club, visit the field and watch a St. Louis Cardinals game with three friends in a field box; a party suite for 30 people at a Cardinals game; a visit to the GM’s private box with dinner and drinks, plus four infield box seats; an in-studio visit to Sports Open Line and dinner at Mike Shannon’s Steaks and Seafood; four tickets, on-the-field batting practice access and a visit to the broadcast booth; an opportunity to hit the links in style with gift cards to Mister Guy Clothiers and Golf Discount, plus a foursome at Algonquin Golf Club; Navy SEAL training for a day; and a BMW Carbon Racer Bike.

It does indeed “take a village” – special recognition to our hard-working VOLUNTEERS under the direction of Golf Committee Co-Chairs, Matt & Annemarie Schumacher, and committee members Matt LaMartina, Mark Lawson, Alan Lemley, Barry Roufa, Dave Sadler, and Grant Washburn; as well as John Basilico, Kay and Rebecca Bruchhauser, Ann Cook, Andy Dalin, Elaine Dreher, Karl Guyer, Barb Koch, Benjy and Joyce Levin, Craig Miller, Nancy Schillinger, Marilyn Warren and Sherre Wiedemann. A big thank you to our tireless volunteers from Scottrade who spent the day with us as part of their community day of service: Andrew Barco, Matt Black, Mary Ferry, KC Grun, Scott Deters, Andrea Hussey, Sarah Krantz, Krishna Rao, Matt Spector and Mary Lou Sullivan.

Please consider volunteering to join our golf committee, or if you wish to receive an invitation for next year’s golf tournament to be held on Monday, May 16, 2016, at Algonquin Golf Club, let us know by phone: 314-362-3299 or e-mail: malmengor@apdaparkinson.org.
HONORING
Stephanie Alport on a speedy recovery
Pam & Jerry Brown

John Basilico on his birthday and with appreciation
Debbie & Karl Guyer

Mr. & Mrs. Harvey Brown on their 65th anniversary
Rita Eiseman

Mr. & Mrs. Robert Brown on their special anniversary
Pam & Jerry Brown

Mr. Lee Chazen
Pam Sherman Brown

James Grates
Lisa Knoll

Dick & Sue George
Rochelle Weiss & Steve Lobe

Marilyn & Arnold Goldman on their 40th anniversary
Steve & Marilyn Darlick
David & Sabina Garfinkel
Herbert & Nancy Seidel

Ralph P. Goldsticker, Jr., on receiving the French Legion of Honor Medal
Larry & Andi Goldsticker
Debbie Guyer

Jean Griford for her work in the Parkinson community in St. Genevieve
Jack Stronsider, Sr.

Jim Heddinghaus
Mr. & Mrs. Arthur Ray Heath

Carole Kalish on her special birthday
Carol & Bruce Rosen

Mark Kodner on his birthday
Penny Kodner

Jim & Joan O’Driscoll on their 50th anniversary
Dale & Norma Plank

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Cassville School District R-IV

Sid Silverman on his 85th birthday
Debbie & Tab Cohen

Our 49th anniversary
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Jack Stronsider on his 90th birthday
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Barbara Lindhorst

Terri & Bill Taylor on their anniversary
Roz Gadd

IN MEMORY OF
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Dolores Palmer
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Carol W. Szewda
Nicole Timlin & KECC Family
J. Kent Underwood
Gary & Donna Vandiver
Lea Virtel

Clarence & Mary Nina Wagner
Mary & Raymond Watts
Peter & Teresa Wetzel
Carl & Rose Will
Ray & Mary Winkler
Loretta & Charles Wittenberg
Mary & Terry Wittenberg

Tony Germer
Patricia Anghilante
Helen Goldsticker
Andi & Larry Goldsticker

Ismael Herrera
Anthony & Kathleen Bommarito

Marigrace Hoffman
Gloria Hurley

Robert Hofmann
Sandra & Jerry Barklage
Richard & Lisa Beckmann
Alan & Connie Button
Defiance & Wright City Quarries
Jerry Lee & Billie Jean Diekamp
Herb & Lisa Homeyer
Russell & Robin Illy
Lucille Kasper
Glen & Kari Koeven
Joanne Koeven
Candace & Randy Politte
Arlene Rothermich
Tim & Barb Schwane

Joan Hollander
Rita Eiseman

Marvin Holtzman
Fran & Sid Axelbaum
Roz Gad

Richard Karney
Carol Fantich
Marsha & Steve Funk
Minnie Kaplan
Sandra Turk & Family

Robert Klefisch
Richard Klefisch

Allen Kolons
Sharna Kohner

Joseph Koreen
Kathi, Stuart, Jamie, Laura &
Corey Rosenberg

John L. Krieger
The Krieger Family

Sharon Lambing
Larry & Kay Beckett
Rita Boero
James “Red” Boyle
Tom & Mary Bruhnkuhl
Bonnie Cochrane
Darlene Cole
Concordia Lutheran Church
Carol Dierker
Fraternal Order of Eagles Aux 
#3781
Ann Gratza & Ervin J. Vlasak
Bill & Beverly Johnson
Karen Kilcullen & Dan Scheu
Jo-Di Lambing
Roger & Suzanne Louderman
Jay & Gina Maben
Gene & Jackie Martin
James & Barbara Massie
Wanda & Herman Merkel
Missouri State Auxiliary
Missouri State Auxiliary Officers
Norma Jean Parker
Russ & Emmy Rapp
Helen M. Ruwe & Family
Doma Schatz
Hester Taylor
Billie & Jack Tyler
Doug & Diane Vaughn
Patricia Webb

Iris Levitt
Debbie & Karl Gayer

Glenn Linke
Mike & Bernice Resnick

Vance Lischer
The Lapp Family

Nick J. Ludwig
Diane Ludwing

Elizabeth Mack
Beverly & Jerry Silverman

Tom A. Manglis
Anthony & Susan Cassimatis

Brigida Manzo
Tom Gebken
Greg & Francesca Grass
Gene & Cindy Morgenthaler
Amy & Joe Wolff

John Mayes
Elizabeth Balf
John & Colleen Hoercher
Judy Krakse
M. & Mrs. Eugene Munier
Brenda Randall
Kurt Schroeder
Dave & Lisa Tiedemann

Ed McPherson
CMW Equipment

Robert Miller
Barbara Miller

Evelyn Mitchell
Betty Tate

Ramon Morganstern
Herb & Nancy Seidel
Stan, Sally & Marczi Zimmerman

Fred Oertt, Jr.
Guarantie Electrical

Dr. Sam Pagano
Stan & Angie Klearman

Don Pallo
Roberta Hayman
Jeffrey & Judy Pass
Cheryl Perl

Angelo Panourigas
Louis & Catherine Anastasio
Renée Becker
Ron & Elaine Beem
Stephan & Melissa Bruce
Janell Brucker
Ken & Terri Goodwin
Kenneth & Sharon Goodwin
Gus & Pat Hawkins
Rich & Phyllis Hawkins
The Irwin Family
Brian & Deed Kelley
Peter & Judith Lattal
Jason Martin
Pat & Sandy Martin
Dr. Richard Schainker
South Side Small Group
Jane & Sandy Thal
Sergio & Veda Toulos
Bob & Virginia Yale

Jim Peterson
Jean Peterson

Franklin Pinkston
Gail Gargac
Denise & Andrew Jackson

Tom & Bev Nance
The Niemeiers
Brandi Oller & Pilar Gallardo-Oller
Jerry Volak
David & Karen Warren

Rae Ann Powers
Mr. & Mrs. Walter A. Kempter
Pam & Ed Ponder
Catherine M. Staten

Ali Rakers
Lyn & Bill Heaton

Mary Ann Rielly
Thomas J. Rielly

Thomas Rosenburg
Neal & Lynn Grannemann

Elfrieda Roth-Roffy
Paul Roth-Roffy

Charles Ruscha
David Probstfield

Goldie Satz
Bill & Terri Taylor

Leo Schade
Kathleen Stones
Sharon Wein

Jackie Schmidt
Larry Schmidt

Paul Schmittling
Mary Conrey
Mike & Gail Glover
Kari Hercules
Susan & John Jasiewicz
Sandy & Chris Knee
Michael & Pam Reitmeyer
Ray Schmitter & Families
Judith Shoemaker
Charles & Debra Thacker
Kris Westhoff

Selma Schmitsky
Roberta Hayman

Elizabeth Schweizer
Gail & Larry Glenn

Jannette Schwpegue
Jerome & Cynthia Schonhoff

Ely Shrauner
Bill & Roberta Abraham
Katharine Abraham
Sarah Abraham
George & Abir Bazlamit
Claude Bernard
Elizabeth & William Caspari
James & Carlee Caspari
Matthew Caspari
Deb & Jeff Clinebell
Betty & Jim Dowd
Matthew & Amy Dowd
Michael & Jessica Friedlander
Pat Gibbons
Mr. Edward Greenberg
Gary & Carol Hamilton
Annaliese & Wayne Hanebrink
Margaret & Martin Israel
Wilhelm Neufeldt
Ruby E. Quarterman
John & Ray Sandrett
Barbara Shrauner
James Shrauner
Jay & Cynthia Shrauner
Penelope Shrauner

Raymond Siebert
Fred Jones

John Skurat
Frank & Marilyn Schoeck

Paul L. Slepko
Ted & Audrey Sanders
Joan & Thomas Thompson

Charles Standley
Diane & Dick Stonecipher

Donald Symank
Bob & Pat Dillman
Frank & Vanda Dillman
Morris & Joyce Huelskotter
William & Jan Lauber

Charles “Bud” Teeter
Allstates WorldCago Family
Ron & Lisa Ameln
Don Hagemier & Clara Veal
Kenneth Mueller
Gwynne Seigel
Leslie Wilson

Hatice Thal
Renee & Gary Harrison

Michael Tomko
Stuart & Kathi Rosenberg
George Trakas, Jr.
Ed & Robin Biermann
Tim & Jeannie Hallemann
Greg & Kerri Klein
Kathy Mester
David & Kathleen Sandknap
Bruce & Caryn Sandweiss

Gordon E. Wall
Marilyn Wall

Ruth Warhoven
Charles & Mary DeLong

Vernon Weing
Sandra Aye
Donald & Patricia Berendt
Carol Beftejewski
George & Janice Brennan
Mr. & Mrs. Ernesto Cabrera
Russell & Bonnie Farrah
Joyce A. Foster
Jackie & Dennis Hinderliter
Jim & Marjorie Leuthausen
Raymond & JoAnn Orr
Peggy Piekariski
Dale & Norma Plank
Dan & Lori Schmidt
Jim & Kathy Schweigert
Patrick Snow
Kermit Shelley & Immacolata
Bergman-Shelley
W.B & Norma Shelley
Dave & Jean Stegmann
Bob & Rhonda Stuckey
Dorothy Wernemann
Tom & Ruth Wiley

Norma Zieneguard
Don Zieneguard

Theodore Zinselmeier
Jack Strosnider, Sr.

GENERAL GIFTS
UP TO $99

Sandra Aye
Donald & Patricia Berendt

Barbara Schonhoff
Ely Shrauner

Eulalie Balf
Evelyn Schmitter

Mary Ann Rielly

John Skurat

Donald Symank

Charles Standley

John Skurat

Paul L. Slepko

Raymond Siebert

Mary Ann Rielly

Goodrich Electric

Guarantee Electrical

APDA–GREATER ST. LOUIS CHAPTER
AUGUST 2015 LINK

9

UP TO $99

GENERAL GIFTS

$100 – $499

Bill & Nancy Anderson
Robert Babiore
Ed & Rita Balk
Herb & Marge Billins
Bill Billings
Jean Cody
Col. & Mrs. Robert Coulter
David & Patsy Dalton
EDM Millipore
Bill & Erica Gerth
Mr. & Mrs. Michael J. Honigfort
Ladue Chapel Women’s
Association
Christel Maassen
John & Susan Rothenheber
Cynthia E. Smalley
Marilyn F. Wall
Gene & Patricia Wittman

GENERAL GIFTS

$500 – $999

James Holsinger
Marjorie A. Prunty
Mary Stein

GENERAL GIFTS

$1,000 – $4,999

Thomas H. Benton, Jr.
Rotonda Foundation
Rich & Cheryl Schumacher
Southern Illinois Support Group

GENERAL GIFTS

$5,000 – $9,999

Lucy Bauman
Marilyn Decker
George Von Hoffmann Foundation

GENERAL GIFTS

$10,000 AND OVER

Guarantee Electrical

THRIVENT CHOICE

DOLLARS

Rilla Fisher-Pugh & Dennis Pugh
Kevin Hunter
Carolyn Long
David Long
Louise Munsik
Roger Peters
Flora Sanders

Richard Distler
Ronald Dunham
Col. Walter & Marjorie Evans
Norman V. Giovannini
Gary Jones
George Kantis
Edith Kapferstein
Michael & Nancy Klein
David Lansdown
Hadassah & Sanford Lebman
James & Mary Lister
William & Rozanne Mannen
Naomichi & Yuko Masaki
Glenn & Carol McDevitt
Richard Saffety
Kathleen Saftff
Charles & Leona Sarkisian
David Wesse
K.L. & Mary Young
Richard & Margaret Zimmerman
Drug Expense Relief
Kathy McVoy, Caregiver

Whee! Into the coverage gap I went. How much for entacapone (generic for comtan)? Did you say, $888, and the next time $768? REALLY! Down the wicked medicine slide we went into the coverage gap. My husband, Ken, and I have had to contend with the mammoth costs of his PD drugs for a couple of years. Ken, who has had Parkinson’s for 9 years now, takes entacapone 7 times a day. He takes other drugs as well, but this one is the greediest emptier of pockets of them all.

Since we fall into a middle class coverage gap, it has been difficult to find assistance in reducing the cost of medications. We knocked on several doors to figure out how to lessen the expense. If you do not have insurance or your income is less than $30,000, you can qualify for help with the Prescription Partnership Association, www.pparx.org. I called the manufacturer of the drug, Novartis, but they don’t offer assistance. A very helpful fellow caregiver sent me to check out the Canadian mail order pharmacy route, which can be a good choice for some as they do offer reduced costs. Unfortunately, they wouldn’t make a big difference for us because of the large amount of the drug Ken takes. You can go to affordabledrugs.com to learn more about this program.

So, finally I spoke with Debbie Guyer, Executive Director of the Greater St. Louis Chapter. She suggested contacting Stacey Barton, a Social Worker with the Movement Disorder Center. Stacey was the caring, competent companion who walked me through the website Medicare.gov. You can go to the site and list all the drugs you need and compare which drug plan is most cost effective. I had visited the site before, but I didn’t trust my assessment. I grew up dialing a phone and talking with people. How do you ask a computer, “Are you sure?” So, if you are like me and would like a guide through the process, ask a family member or friend, someone who is comfortable with the tech territory.

Just when you thought you could relax with this fairly simple solution, “heads up!” Stacey reminded me to check my drug plan each year. Plans change year to year and may not always cover the same drugs or cover them at the same cost.

So, I say, “Yay for a community of caring companions!” There are rocks along the path, and there are helpers to manage the stumbling. Thank you!

A Slam Dunk!
The Cassville R-IV School District high school girls’ basketball team raised funds and awareness about Parkinson disease on February 9, 2015, at the annual home game against Monett High School. This year they raised $500 in honor of Coach Chris Shore’s father, Charles, who battles Parkinson disease every day. This represents the second contribution made as a result of this game; the first, which raised $448, occurred in 2013. We hope the community continues this tradition when Monett visits Cassville every other year.

Got Pizza?
While raising awareness about Parkinson disease every Thursday during this past April, members of the Greater St. Louis APDA could dine in or carry out from all St. Louis locations of California Pizza Kitchen (CPK). CPK contributed a percentage back as a fundraiser for the Greater St. Louis APDA which resulted in receipt of $548.55 for our cause! Thank you for your support again this year.

Bike-Swim-Run Triathlon
The Chawla family raised $1,300 this past April and May by participating in a bike/swim/run triathlon among their family and friends to honor the memory of loved one, Mr. Tilak Chawla. They exceeded their goal by getting multi-generations of the family members involved in this worthy cause. What a lovely tribute to a gentleman who holds such special meaning for so many.

One-of-a Kind Bob Gibson Hall of Famer Painting Prints Available
This unique painting of St. Louis Cardinals Hall of Famer Bob Gibson was painted by local artist Kyle D. Lucks and auctioned at the Jack Buck Memorial Golf Classic held in May, 2015. Kyle has offered to sell prints of the painting and donate all of the proceeds to the APDA Greater St. Louis Chapter. To purchase your print, visit Kyle’s website at http://www.kylelucks.com/product/bob-gibson/.
The Worst Advice for Family Caregivers: Parent Your Aging Parents

Howard Gleckman, author of the book, Caring for Our Aging Parents.

In the always-complex, often-painful world of family caregiving, there is no worse advice than this: When your parents need help, you must reverse roles and become their parents.

Here is the reality: If you are the adult child of an aging parent, you will always be their child, and they will always be your parent. They may need your help with the most intimate personal care. But you will never become their parent.

I saw this all the time when I was researching my book, Caring for Our Parents. I had the opportunity to spend as long as two years with people who needed assistance and their family caregivers. I saw heartwarming successes and sad failures. Often the difference was the ability of adult children to understand their roles.

Courtland Milloy, in his column for the Washington Post, offered this guidance: “Some elder-care experts say that when aging parents stop acting in their best interest, the grown children must reverse roles and simply make them do the right thing.” As he learned, this advice is so wrong on so many levels.

To start, what is the “right thing”? Who are you to decide what is right? As a matter of law and, I believe, ethics and morality, each of us gets to decide the “right thing” for our own life, as long as we are cognitively able and our choice does not harm others.

A wise man once said it like this: “When I was 22, I did some things my parents thought were remarkably stupid. But I was an adult and they were my choices. Now, my parents may be doing some things that I think are remarkably stupid. But they have the same right to make mistakes as I did.”

Put yourself in the position of an aging parent. As you become physically frail and cognitively limited, you lose control of your life. All those day-to-day decisions that healthy people take for granted—when to go to the movies, when to eat, when to walk across the room and even when to go to the bathroom—are increasingly shared with others. It can be embarrassing and demeaning.

And it is why a big part of frail old age is about maintaining independence and respect.

Now comes your child. He may be 50 years old, but he is still your child. And he is saying: “Mom, you’ve got to go to the doctor.” “You’ve got to stop driving.” “You’ve got to move to assisted living.” He may have just parachuted into town for a few days. He seems rushed and impatient.

To his credit, Milloy finally got it, despite starting out with that awful “reverse roles” advice.

Like the proverbial bad penny, this parenting your parents business keeps coming back. Years ago, when I was writing for Business Week, an editor suggested a consumer caregiving column. It would be called, you guessed it... “Parenting Your Parents.” I told her I’d love to write the column but the name had to go. That was the last I heard about the idea.

This article originally appeared in Forbes Magazine on September 4, 2013

Needless to say, this is not a great environment in which to make decisions.

What’s the alternative? As much as possible, share decision-making. As the adult child, never start any sentence with the words: “Mom, you’ve got to...” Instead, try, “What do you think we should do?” Help them choose. But work together as much as you can.

Of course, if a parent or other relative is emotionally or cognitively incapable of making decisions, you may have to step in. But that is much less common than many suppose.

To his credit, Milloy finally got it, despite starting out with that awful “reverse roles” advice.
**Fiber must have fluids** Next, consider the need of fluid. The fiber particles you eat require water in order to swell up and keep the stool soft. Aim for at least six, 8 ounce servings of fluids each day, about half of which, ideally, would be plain water. Coffee and tea count, but the caffeine also causes some water loss. When taking medications, take them with an 8 ounce glass of water, rather than just the sip needed to swallow a pill. Other sources of water include soups, juices, smoothies, and a bowl of chopped mixed fruit (fruits and vegetables are naturally high in water content).

**Probiotics for gut health** Last, but just as important, consider the use of probiotics to maintain colon health. Although you can purchase gelcaps containing various probiotics, a much less expensive way is to eat fermented foods frequently—sauerkraut and kimchee are examples of fermented foods. Alternatively, make your own kefir. Kefir grains are small particles containing a wide variety of both bacteria and yeasts. When placed in milk, coconut milk, or sweetened water, the kefir grains consume the sugars, producing a fluid rich in microorganisms that are needed by the colon. For information and directions on making different kinds of kefir, visit the following websites:

- [http://www.wikihow.com/Make-Kefir](http://www.wikihow.com/Make-Kefir)
- [http://www.waterkefir.org](http://www.waterkefir.org)

A recent study showed that people with PD have an imbalance of microorganisms in the gut. These friendly organisms can also be depleted by use of antibiotics or a diet deficient in the prebiotic substances they rely on for food. Prebiotics are certain types of fiber-fructo-oligosaccharides and inulins—which are not digested by humans but pass into the colon and are used as food by these friendly organisms. Eating a variety of high-fiber foods will ensure that your colon receives prebiotics for the probiotics to consume.

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**Managing Constipation in Parkinson Disease** continued from page 2

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**SEWING THE SEEDS OF OPTIMISM**

*20th Annual APDA Fashion Show, Luncheon and Auction*

We’re excited to bring you another delightful afternoon of fashion, delicious food and gifts from a silent auction filled with tastes of our town restaurant gift cards/certificates and one-of-a-kind items. Proceeds from this event will be used to support APDA’s dual mission—*to ease the burden and find the cure* by expanding patient programs and services to improve quality of life for individuals and family members and funding promising Parkinson research, which seeks to further identify causes and ultimately find a cure for Parkinson disease.

*Invite your family, friends and neighbors!*

We are thrilled to have Kelly Jackson, Anchor KSDK-TV and KTRS-Radio, and creator of Aarff.com and Jennifer Blome, Director of Humane Education, APD Missouri, and former Anchor of KSDK-TV morning newscast, *Today in St. Louis*, as our Masters of Ceremonies and to present fall fashions from some of St. Louis’s finest boutiques including Mister Guy Clothiers (Men’s and Women’s fashions), Distinctions (formalwear), Vie, and Paperdolls.

Doors open for the silent auction and wine reception at 11:00 a.m., the luncheon will begin at 11:45 a.m., and the fashion show starts at 1:00 p.m. on **October 12, 2015**, at the Sheraton Westport Chalet. The cost will be $70 per guest.

**How can you help?** Please consider becoming a sponsor. As a sponsor, you or your business will receive prominent placement in our program and on signage at the event, plus special seating at the fashion show. In addition, your name will be featured in the November *LiNK* newsletter distributed to over 9,500 homes and businesses across Missouri and Illinois. Sponsorships begin at $500 with many levels to appeal to any supporter.

For more information about the fashion show and sponsorships, visit our website at [www.stlapda.org](http://www.stlapda.org) or call the APDA office at **314-362-3299**. If you haven’t received an invitation in the past and would like to receive one this year, please send an email to malmengor@apdaparkinson.org or give us a call. We’ll gladly include you on our guest list! We hope you, your family and friends will join us to make this year’s event another “fashionable” success!
# Missouri Support Group Calendar

Our support groups meet once a month or as noted. Support group day and time may change periodically. For current updates on support groups and exercise classes, check our website, [www.stlapda.org](http://www.stlapda.org), or call the APDA Information & Referral Center or the facilitator. Information that has changed since the last LiNK appears in **bold**.

<table>
<thead>
<tr>
<th>CITY</th>
<th>COUNTY</th>
<th>MEETING SITE</th>
<th>DAY OF MEETING</th>
<th>TIME</th>
<th>LEADER(S)</th>
<th>PHONE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ballwin</td>
<td>St. Louis</td>
<td>Meramec Bluffs Care Center 40 Meramec Trails Dr., Activities Rm.</td>
<td>4th Tuesday</td>
<td>2:00 PM</td>
<td>Gayle Truesdell</td>
<td>636.923.2364</td>
</tr>
<tr>
<td>Cape Girardeau</td>
<td>Cape Girardeau</td>
<td>Cape Girardeau Public Library 711 N Clark Street, Oscar Hirsch Room</td>
<td>3rd Monday</td>
<td>6:00 PM</td>
<td>Desma Reno, RN, MSN</td>
<td>573.651.2939</td>
</tr>
<tr>
<td>Chesterfield</td>
<td>St. Louis</td>
<td>APDA Community Resource Center 1415 Elbridge Payne, Suite 150</td>
<td>1st Tuesday</td>
<td>10:30 AM</td>
<td>Mary Buck</td>
<td>636.532.6504</td>
</tr>
<tr>
<td>Chesterfield</td>
<td>St. Louis</td>
<td>For Caregivers Only APDA Community Resource Center 1415 Elbridge Payne, Suite 150</td>
<td>2nd Monday</td>
<td>10:30 AM</td>
<td>Dee Jay Hubbard, PhD</td>
<td>314.362.3299</td>
</tr>
<tr>
<td>Columbia</td>
<td>Boone</td>
<td>Lenoir Community Center 1 Hourigan Community Drive</td>
<td>1st Thursday</td>
<td>4:00 PM</td>
<td>Patsy &amp; David Dalton</td>
<td>573.356.6036, 573.434.4569</td>
</tr>
<tr>
<td>Creve Coeur</td>
<td>St. Louis</td>
<td>Pre/Post-DBS Group Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl., CLI Rm. 419</td>
<td>3rd Tuesday</td>
<td>6:30 PM</td>
<td>Joe Vernon</td>
<td>314.614.0182</td>
</tr>
<tr>
<td>Creve Coeur</td>
<td>St. Louis</td>
<td>Young Onset Living and Working with PD Missouri Baptist Medical Center 3015 N. Ballas, Main Parking Garage 4th fl., CLI Rm. 419</td>
<td>3rd Tuesday</td>
<td>6:30 PM</td>
<td>Doug Schroeder</td>
<td>314.306.4516</td>
</tr>
<tr>
<td>Festus/Crystal City</td>
<td>Jefferson</td>
<td>Disability Resource Association 130 Brandon Wallace Way</td>
<td>3rd Tuesday</td>
<td>1:00 PM</td>
<td>Penny Roth Sara Dee</td>
<td>636.931.7696 x129</td>
</tr>
<tr>
<td>Florissant</td>
<td>St. Louis</td>
<td>Garden Villas North 4505 Parker Rd.</td>
<td>4th Thursday</td>
<td>11:00 AM</td>
<td>Nancy Robb</td>
<td>314.869.5296</td>
</tr>
<tr>
<td>Jefferson City</td>
<td>Cole</td>
<td>Capital Regional Medical Center SW Campus, Cafeteria</td>
<td>3rd Wednesday</td>
<td>3:00 PM</td>
<td>Jennifer Urlich, PT David Urlich</td>
<td>573.632.5440, 573.796.2395</td>
</tr>
<tr>
<td>Joplin</td>
<td>Jasper</td>
<td>Byers United Methodist Church 1730 S. Byers, Gymnasium</td>
<td>Every Monday</td>
<td>3:00 PM</td>
<td>Nancy Dunaway</td>
<td>417.623.5560</td>
</tr>
<tr>
<td>Kansas City</td>
<td>Jackson</td>
<td>VA Medical Center 4801 Linwood Blvd. Hall of Heroes Room</td>
<td>3rd Tuesday</td>
<td>11:00 AM</td>
<td>Jesus Torres Nikki C. Caraveo, RN, BSN, CNRN</td>
<td>816.861.4700 x56765</td>
</tr>
<tr>
<td>Kirkwood</td>
<td>St. Louis</td>
<td>Kirkwood United Methodist Church 201 W. Adams, Room 201</td>
<td>4th Tuesday</td>
<td>7:15 PM</td>
<td>Terri Hosto, MSW, LCSW</td>
<td>314.286.2418</td>
</tr>
<tr>
<td>Ladue</td>
<td>St. Louis</td>
<td>The Gatesworth 1 McKnight Place</td>
<td>2nd Wednesday</td>
<td>1:00 PM</td>
<td>Maureen Neusel, BSW</td>
<td>314.372.2369</td>
</tr>
<tr>
<td>Lake Ozark</td>
<td>Camden</td>
<td>Lake Ozark Christian Church 1560 Bagnell Dam Blvd.</td>
<td>3rd Thursday</td>
<td>Noon</td>
<td>Patsy &amp; David Dalton</td>
<td>573.356.6036, 573.434.4569</td>
</tr>
<tr>
<td>Poplar Bluff</td>
<td>Butler</td>
<td>Poplar Bluff Regional Medical Center 3100 Oak Grove Rd. Ground Floor Education Room 3</td>
<td>2nd Monday</td>
<td>6:00 PM</td>
<td>Charles Hibler register with Beryl or Dana</td>
<td>573.785.6222, 855.444.7276, 573.778.9355</td>
</tr>
<tr>
<td>Rolla</td>
<td>Phelps</td>
<td>Phelps County Regional Medical Center, Pulaski Room, 1000 W. 10th St.</td>
<td>4th Thursday</td>
<td>2:30 PM</td>
<td>Sarah Robinson</td>
<td>573.201.7300</td>
</tr>
<tr>
<td>South St. Louis</td>
<td>St. Louis</td>
<td>Garden Villas South 13457 Tesson Ferry Rd.</td>
<td>2nd Wednesday</td>
<td>10:00 AM</td>
<td>Jack Strosnider</td>
<td>314.846.5919</td>
</tr>
<tr>
<td>Springfield</td>
<td>Greene</td>
<td>Mercy Hospital 1235 E. Cherokee</td>
<td>2nd Thursday</td>
<td>2:00 PM</td>
<td>Valerie Givens, RN</td>
<td>417.820.3157</td>
</tr>
</tbody>
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<tbody>
<tr>
<td>St. Peters</td>
<td>St. Charles</td>
<td>Spencer Road Library 427 Spencer Rd., Room 259</td>
<td>1st Tuesday</td>
<td>1:00 PM</td>
<td>Sherrie Rieves, Ann Ritter RN</td>
<td>636.926.3722</td>
</tr>
<tr>
<td>Trenton</td>
<td>Grundy</td>
<td>Royal Inn 1410 E. 9th Street</td>
<td>1st Thursday</td>
<td>10:00 AM</td>
<td>Novy &amp; Mary Ellen Foland, Gloria Koon</td>
<td>660.357.2283, 660.485.6558</td>
</tr>
<tr>
<td>Washington</td>
<td>Franklin</td>
<td>Washington Public Library 410 Lafayette Avenue</td>
<td>2nd Monday</td>
<td>6:30 PM</td>
<td>Carol Weber</td>
<td>314.713.4820</td>
</tr>
<tr>
<td>Webster Groves</td>
<td>St. Louis</td>
<td>Bethesda Institute 8175 Big Bend Blvd., Suite 210</td>
<td>Last Friday</td>
<td>10:30 AM</td>
<td>Laurel Willis, BSW</td>
<td>314.373.7036</td>
</tr>
<tr>
<td>Webster Groves</td>
<td>St. Louis</td>
<td>Laclede Groves 723 S. Laclede Station Rd.</td>
<td>3rd Wednesday</td>
<td>3:00 PM</td>
<td>Dina Spies</td>
<td>314.446.2594</td>
</tr>
</tbody>
</table>

## Illinois Support Group Calendar

Our support groups meet once a month or as noted. Support group day and time may change periodically. For current updates on support groups and exercise classes, check our website, [www.stlapda.org](http://www.stlapda.org), or call the APDA Information & Referral Center or the facilitator. Information that has changed since the last LiNK appears in **bold**.

<table>
<thead>
<tr>
<th>CITY</th>
<th>COUNTY</th>
<th>MEETING SITE</th>
<th>DAY OF MEETING</th>
<th>TIME</th>
<th>LEADER(S)</th>
<th>PHONE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alton</td>
<td>Madison</td>
<td>Senior Services Plus 2603 N. Rodgers Ave.</td>
<td>2nd Tuesday</td>
<td>9:30 AM</td>
<td>Kim Campbell</td>
<td>618.465.3298 x146</td>
</tr>
<tr>
<td>Belleville</td>
<td>St. Clair</td>
<td>Southwestern Illinois College (PSOP) 201 N. Church St., Rm 106</td>
<td>2nd Monday</td>
<td>1:30 PM</td>
<td>Jodi Gardner</td>
<td>618.234.4410 x7031</td>
</tr>
<tr>
<td>Carbondale</td>
<td>Jackson</td>
<td>Southern IL Healthcare Headquarters University Mall</td>
<td>1st Wednesday</td>
<td>1:00 PM</td>
<td>Bill Hamilton, M.D.</td>
<td>618.549.7507</td>
</tr>
<tr>
<td>Centralia</td>
<td>Washington</td>
<td>Heritage Woods of Centralia 2049 E. McCord St.</td>
<td>2nd Wednesday</td>
<td>2:00 PM</td>
<td>Dennis Krupp, Betty Evans, Helena Quaid</td>
<td>618.545.6597, 618.533.0224, 618.493.6064</td>
</tr>
<tr>
<td>Champaign</td>
<td>Champaign</td>
<td>Savoy United Methodist Church 3002 W. Old Church Road</td>
<td>Every Monday</td>
<td>10:00 AM</td>
<td>Charles Rohn, Chuck Arbuckle</td>
<td>217.549.6167, 217.586.3100</td>
</tr>
<tr>
<td>Decatur</td>
<td>Macon</td>
<td>Westminster Presbyterian Church 1360 West Main Street</td>
<td>3rd Thursday</td>
<td>1:30 PM</td>
<td>John Kileen</td>
<td>217.620.8702</td>
</tr>
<tr>
<td>Glen Carbon</td>
<td>Madison</td>
<td>The Senior Community Center 157 N. Main St.</td>
<td>3rd Wednesday</td>
<td>10:30 AM</td>
<td>Nancy Goodson, Rich Rogler</td>
<td>618.670.7707, 618.288.3297</td>
</tr>
<tr>
<td>Greenville</td>
<td>Bond</td>
<td>Bond County Sr. Center 1001 E. Harris Ave.</td>
<td>4th Monday</td>
<td>10:30 AM</td>
<td>Anna Oestrech</td>
<td>618.664.1465</td>
</tr>
<tr>
<td>Greenville</td>
<td>Bond</td>
<td>Bond County Sr. Center Baumberger Comm. Rm. CAREGIVERS ONLY</td>
<td>4th Friday</td>
<td>1:00 PM</td>
<td>Anna Oestrech</td>
<td>618.664.1465</td>
</tr>
<tr>
<td>Jacksonville</td>
<td>Morgan</td>
<td>Passavant Area Hospital 1600 W. Walnut–Meeting Room 2</td>
<td>1st Wednesday March-December</td>
<td>6:00 PM</td>
<td>Karen Ladd</td>
<td>217.377.4973</td>
</tr>
<tr>
<td>Mattoon</td>
<td>Coles</td>
<td>First General Baptist Church 708 S. 9th St.</td>
<td>Last Tuesday</td>
<td>1:30 PM</td>
<td>Roy and Kay Johnson</td>
<td>217.268.4428</td>
</tr>
<tr>
<td>McLeansboro</td>
<td>Hamilton</td>
<td>Heritage Woods – Fox Meadows 605 S. Marshall Ave., Dining Room</td>
<td>1st Wednesday</td>
<td>1:00 PM</td>
<td>Paula K. Mason</td>
<td>618.643.3868</td>
</tr>
<tr>
<td>Springfield</td>
<td>Sangamon</td>
<td>St. John’s Rehab. @ Fit Club South 3631 S. 6th. Street #C</td>
<td>3rd Sunday Odd number lines 1,3,5,7,9,11</td>
<td>2:00 PM</td>
<td>Kelly Neumann, PT</td>
<td>217.483.4300</td>
</tr>
</tbody>
</table>
# Exercise Classes

The APDA now offers 17 exercise classes that meet weekly. Exercise is essential to managing Parkinson symptoms and slowing the progression of the disease. Our patient services funding comes from donations and is limited, so we encourage those who wish to attend multiple classes to make a $5 per week donation. This minimal donation helps us defray the cost of the classes which run around $10 per person to cover the instructors’ salaries, room rentals, and equipment. This donation request is on an honor system, and we don’t turn anyone away from attending as many classes as they choose. To make a donation for exercise classes, use the blue envelope in your newsletter and note that it is for exercise class. Many people choose to pay quarterly to reduce the number of checks they write each month. Any amount you can contribute is used exclusively for our patient services to keep these programs free or at little cost to our patients.

Our exercise classes meet once a week or otherwise as noted. Information that has changed since the last LiNK appears in **bold**. Attend one class per week at no charge, or for $20/month attend as many classes as you want. No RSVPs are required. Check our website, [www.stlapda.org](http://www.stlapda.org), or call to find out any changes since publication.

<table>
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<tbody>
<tr>
<td>Clayton</td>
<td>St. Louis</td>
<td>The Center of Clayton 50 Gay Ave., Mind/Body Room</td>
<td>Wednesday &amp; Friday</td>
<td>2:00 PM</td>
<td>Mike Scheller, PTA</td>
<td>314.289.4202</td>
</tr>
<tr>
<td>Chesterfield</td>
<td>St. Louis</td>
<td>St. Luke’s Deslodge Outpatient Center 121 St. Luke’s Center Drive Conference Rooms 1 &amp; 2</td>
<td>Monday</td>
<td>10:00 AM</td>
<td>Sarah Farnell, OT</td>
<td>314.205.6934</td>
</tr>
<tr>
<td>Chesterfield</td>
<td>St. Louis</td>
<td>Friendship Village 15201 Olive Blvd. Friendship Hall-Door 5</td>
<td>Tuesday</td>
<td>1:30 PM</td>
<td>Jessica Andrews</td>
<td>636.733.0180 x7719</td>
</tr>
<tr>
<td>Chesterfield</td>
<td>St. Louis</td>
<td>Parkinson Resource Center 1415 Elbridge Payne, Ste. 150</td>
<td>Monday</td>
<td>1:30 PM</td>
<td>Becky Miller, DPT</td>
<td>314-362-3299</td>
</tr>
<tr>
<td>Chesterfield</td>
<td>St. Louis</td>
<td>Tai Chi APDA Community Resource Center 1415 Elbridge Payne, Suite 150</td>
<td>Wednesday or Friday</td>
<td>10:00 AM 11:30 AM</td>
<td>Craig Miller</td>
<td>314.362.3299</td>
</tr>
<tr>
<td>Chesterfield</td>
<td>St. Louis</td>
<td>Yoga Maryville University, Walker Hall Reservations Required</td>
<td>Wednesday</td>
<td>6:30 PM</td>
<td>Pradip Ghosh, PT, PhD</td>
<td>314.362.3299</td>
</tr>
<tr>
<td>Creve Coeur</td>
<td>St. Louis</td>
<td>Aquatic Exercise Rainbow Village 1240 Daulet Lane</td>
<td>Summer Session July 6-Sept. 11</td>
<td>1:00 PM Tuesdays</td>
<td>Brenda Neumann</td>
<td>636.896.0999 x21</td>
</tr>
<tr>
<td>Florissant</td>
<td>St. Louis</td>
<td>Garden Villas North 4505 Parker Rd.</td>
<td>Tuesday</td>
<td>10:00 AM</td>
<td>Bobby Lautenschleger, PTA</td>
<td>314.355.6100</td>
</tr>
<tr>
<td>Joplin</td>
<td>Jasper</td>
<td>United Methodist Church 1730 Byers Ave.</td>
<td>Monday</td>
<td>2:15 PM</td>
<td>Nancy Dunaway</td>
<td>417.623.5560</td>
</tr>
<tr>
<td>Kirkwood</td>
<td>St. Louis</td>
<td>RehabCare 439 S. Kirkwood Rd., Ste.200 Park in rear</td>
<td>Thursday</td>
<td>1:00 PM</td>
<td>Brandon Takacs</td>
<td>618.971.5477</td>
</tr>
<tr>
<td>Ladue</td>
<td>St. Louis</td>
<td>Tremble Clefs Singing Salem United Methodist 1200 S. Lindbergh Blvd. Lower Level Choir Room</td>
<td>Saturday</td>
<td>1:30 PM</td>
<td>Linda McNair</td>
<td>314.362.3299</td>
</tr>
<tr>
<td>South St. Louis County</td>
<td>St. Louis</td>
<td>Garden Villas South 13457 Tesson Ferry Rd.</td>
<td>Monday</td>
<td>11:30 AM</td>
<td>Mike Scheller, PTA</td>
<td>314.289.4202</td>
</tr>
<tr>
<td>St. Peters</td>
<td>St. Charles</td>
<td>Barnes-Jewish St. Peters Hospital Healthwise Center, 6 Jungermann Circle</td>
<td>Tuesday</td>
<td>11:00 AM</td>
<td>Holly Evans, COTA</td>
<td>636.916.9650</td>
</tr>
<tr>
<td>St. Peters</td>
<td>St. Charles</td>
<td>Aquatic Exercise St. Charles YMCA 3900 Shady Springs Ln.</td>
<td>Summer Session July 6 – Sept. 11</td>
<td>1:45 PM Thursdays</td>
<td>Brenda Neumann</td>
<td>636.896.0999 x21</td>
</tr>
<tr>
<td>Lake Ozark</td>
<td>Camden</td>
<td>Lake Ozark Christian Church 1560 Bagnell Dam Blvd.</td>
<td>Monday</td>
<td>4:00 PM</td>
<td>Alice Hammel, RN</td>
<td>573.964.6534</td>
</tr>
<tr>
<td>Greenville, IL</td>
<td>Bond</td>
<td>Bond County Sr. Center 1001 E. Harris Ave.</td>
<td>Wednesday</td>
<td>10:30 AM</td>
<td>Anna Oestreich</td>
<td>618.664.1465</td>
</tr>
</tbody>
</table>
American Parkinson Disease Association
1415 Elbridge Payne
Suite 150
Chesterfield, MO 63017

Help us manage our expenses by letting us know when you move, if you want to be removed from the mailing list, or if you’d rather receive an electronic version. Just call 314.362.3299 or email guyerd@neuro.wustl.edu to let us know! Thank you in advance for helping us spend our resources wisely!

Remember to use your eScrip card every time you check out at Schnucks grocery stores and earn dollars for APDA Greater St. Louis Chapter!

Check out our Facebook page at www.facebook.com/APDAGreaterStLouisChapter

AUGUST 15, 2015

Hull of a Race – participate in the 10th annual race to raise funds for Parkinson research, held in Hull, Illinois. More information can be found on their website, www.hullofarace.com. Both 5k and 10k race courses are certified. The race is the kickoff for the Hull picnic – featuring a fried chicken dinner that same night.

OCTOBER 12, 2015

20th Annual Sewing the Seeds of Optimism auction, luncheon, and fashion show held at the Sheraton Westport Chalet. Tickets are sold on a first come, first serve basis. More information is available on our website, www.apda.org/services/fashion-show.

OCTOBER 31, 2015

Partners in Parkinsons (PIP) invites you and your family to attend this event in Collinsville, IL. To learn more or to sign up, visit: https://www.partnersinparkinsons.org/apda/saintlouis. Partners in Parkinson’s helps patients and caregivers gain knowledge and support for navigating a Parkinson’s diagnosis and the PD progression in order to optimize care at every stage of the disease. Whether you’re new to Parkinson’s or have been living with the disease for years, attend this free full day of interactive panel discussions and breakout sessions - learn about living with Parkinson disease, building the right care team (including when and how to seek specialist care), ask your own questions, and connect with Parkinson resources in your own community. Browse a resource fair to connect with leaders from your local medical and Parkinson’s community (local clinicians and movement disorder specialists, allied care providers specializing in PD, research sites conducting local studies, and support and advocacy organizations). Partners in Parkinson’s has been developed by The Michael J. Fox Foundation for Parkinson’s Research and AbbVie.

NOVEMBER 15, 2015

Parkinson Educational Program (PEP) featuring Dr. Joel Perlmutter, Debunking Myths About PD, will be held at Congregation Shaare Emeth, 11645 Ladue Rd. in Creve Coeur starting at 2:00 p.m.